

Supplemental Online Content

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eMethods 1. Final Survey Vignettes

eMethods 2. Final Survey Questions

This supplementary material has been provided by the authors to give readers additional information about their work.

eMethods 1. Final Survey Vignettes

- A. Antibiotic selection: Your baby has a serious infection and requires treatment with antibiotics. The medical team is choosing between two antibiotics. Both are effective at treating the infection.
- B. Pressor selection: Your baby is having difficulty maintaining blood pressure and requires treatment with a medication to raise the blood pressure. The medical team is choosing between two medications that can increase blood pressure.
- C. Non-Emergent Intubation: Over the last few days, your baby has been having increased difficulty breathing. The medical team is choosing between either putting in a breathing tube (intubating) so they can use a ventilator to help your baby breathe, or watching to see if the baby improves.
- D. UVC placement: Your newborn will require intravenous (IV) nutrition for at least a week. The medical team is considering either placing an umbilical venous catheter (UVC) into your baby's umbilical vein or continuing to place regular IVs, which don't last as long. The UVC can provide safe IV access for the first two weeks of your baby's life.
- E. PICC placement: Your baby has an infection that will require intravenous (IV) antibiotics for several weeks. The medical team is considering either placing a peripherally inserted central catheter (PICC line) in your baby or continuing to place regular IVs, which don't last as long. The PICC provides life-saving, long-term stable IV access. One possible complication is a blood infection. Another is that the line might move out of the vein.
- F. Lumbar puncture: The doctors think that your baby may have a severe infection and are concerned about a risk of meningitis. The medical team is considering performing a lumbar puncture (LP) to obtain a small amount of cerebral spinal fluid (CSF) for analysis. A lumbar puncture is a test where they put a needle into the spinal canal and take out fluid so they can look at under a microscope. If they don't do a lumbar puncture, they won't be able to test for meningitis.
- G. Blood transfusion for apnea: Your baby is having increased apnea events (stopping breathing for at least 20 seconds) and low blood counts (fewer red blood cells than normal). The medical team is considering whether to do a blood transfusion or whether to wait and see if your baby's condition improves without needing a transfusion.
- H. Tracheostomy: Your baby is having difficulty coming off the ventilator. The medical team is considering performing a tracheostomy operation, or waiting to see if your baby's condition improves with time. A tracheostomy operation creates an opening through the skin of the neck into the windpipe that allows the surgeon to place a tube through the opening. The opening is kept in place for about a year. This would allow long-term ventilator use at home. It may enable your baby to be discharged home more quickly than not performing the surgery.
- I. Breastmilk vs. formula: Your baby is ready to start feeding by mouth. The medical team is considering whether to start feeding with maternal breast milk or to start feeding with formula.
- J. Research participation: Your baby is at a hospital where many of the doctors do research so they can learn how to improve the care of sick infants. The medical team is considering whether to enroll your baby in a research study to learn whether a new medication may decrease rates of vision problems. Your baby would randomly be given either the new medication or a placebo (harmless substance). The study is not designed to help your baby, but might reduce the chance of vision problems if your baby is given the new medication. The study is designed to benefit future babies with a similar medical condition.
- K. Apnea monitor for discharge: Every few days, your baby has stopped breathing for at least 20 seconds, an event called apnea that is seen in premature babies. This is delaying discharge home. The medical team is considering sending your baby home on an apnea monitor. This may allow your baby to go home earlier but would require using the apnea monitor at home for the first month or two after discharge.
- L. Esophageal atresia: Doctors discover that your baby has an abnormal connection in the esophagus, the tube that allows food to go from the mouth to the stomach. Without surgery, your baby will not be able to get milk into the stomach properly and will die. The medical team is considering whether or not to do the surgery.
- M. Withdrawal of care: Your baby has become very sick. This includes a severe bleed in the brain, injury to the kidneys, and difficulty controlling blood pressure. The doctors believe that your baby will probably not survive. If your baby does survive, your baby will have very bad brain damage. The medical team is considering either

continued aggressive treatment or withdrawal of aggressive care. With withdrawal your baby would be expected to die soon, likely within a few hours.

- N. Emergent re-intubation: Your baby has required a breathing tube for the last few weeks. The tube suddenly fell out of place during routine nursing care. Your baby is now working very hard to breathe. The medical team is considering putting back in the breathing tube (re-intubating) so they can restart the ventilator.
- O. Two medications: Your baby has a condition that is serious but can be cured with treatment. Two medications work, but they have different risks. One has a risk of blindness. The other has a risk of learning disability. The medical team is choosing between the two medications.
- P. DNAR: Your baby has become very sick and has had two “code events” in the past day related to low heart rates. These required chest compressions and medications to restart the heart. The doctors believe that your baby will probably not survive. The medical team is considering placing a “Do Not Attempt Resuscitation” (DNAR) order in the chart so that if the heart stops again, they will not try to restart your baby’s heart.

eMethods 2. Final Survey Questions

1. How much **information** do you want about this decision?

1	2	3	4	5
None				very much

2. How much **control** do you want to have over this decision?

1	2	3	4	5
None				very much

3. **Who should make this decision?**

1	2	3	4	5
All parent	Mostly parent	Equally parent and medical team	Mostly medical team	All medical team

4. How much is this decision about **big-picture goals** for your baby?

1	2	3	4	5	6	7	8	9	10
Not at all									very much

5. How much is this a **technical** decision?

1	2	3	4	5	6	7	8	9	10
Not at all									very much

6. How much does this decision **risk harming** your baby?

1	2	3	4	5	6	7	8	9	10
Not at all									very much

7. How much could this decision potentially **benefit** your baby?

1	2	3	4	5	6	7	8	9	10
Not at all									very much

8. How much **medical expertise** does it take to make this decision?

1	2	3	4	5	6	7	8	9	10
Not at all									very much

9. How much **personal experience** do you have with decisions like this one?

1	2	3	4	5	6	7	8	9	10
Not at all									very much

10. How **urgent** is this decision?

1	2	3	4	5	6	7	8	9	10
Not at all									very urgent